344 Patient education: a pedagogic tool for cystic fibrosis transmission and fertility: GENOUTIL

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Objectives: During consultations, teenagers regularly ask "why do I have cystic fibrosis and not my brother or my sister?" "Will my children also have CF?" Speaking about fertility is not easy for parents: At what age? How? It is also difficult for health caregivers.
Methods: For answering these crucial questions, we created a pedagogic tool with some disconnected clothespins, of different colours. The tool also includes 6 pictures, one represents a father, another represents a mother and the other 4 represent babies. During the session of therapeutic education, we ask teenagers what they know about transmission of their disease, and then we give them correct information, helped by this tool. So, they can understand the notion of chance and exclude the parents' culpability. The pedagogic tool allows explications about genetic transmission. Teenagers often ask questions about the transmission to their future children. They understand that determination of spouse's genetic status will be essential. For health caregivers, this moment is an opportunity to speak about fertility and introduce possibilities of medically assisted conception.
Conclusion: Comprehension of genetic transmission of the disease is facilitated by GENOUTIL. Difficulties in fertility can be discussed a long time before the age of having a child, which is better psychologically. The best moment for using this GENOUTIL is probably around 12–13 years, before adolescence. Other adapted circumstances are with parents of a screened baby, to help them explain the disease transmission to their family, and adults CF patients considering having a baby. This tool is easy to build and inexpensive.

345* Decision making in young adults with cystic fibrosis (CF) about risk of infection: a vignette study

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Young people with CF are expected to consider infection risk when making decisions about careers, leisure and social activities and avoid environments associated with increased risk. This study investigated the process by which such decisions are made.
Seven vignettes were written with a consultant microbiologist, each containing at least one decision about exposure to an environment associated with increased risk of infection, but in the context of a potentially desirable activity. For example, one described a situation in which a patient is asked by a friend to go horse riding, which would increase risk of exposure to *Aspergillus*. A further choice (to visit stables) would increase risk.
Young people with CF (n = 8) were asked to make the choices within each vignette, and to verbally describe their reasoning as they did so. Conversations were recorded and subjected to thematic analysis.
The vignettes contained 12 choices involving increased risk. The high risk decision was made on 61% of occasions. Two choices, involving increased risk to *Pseudomonas aeruginosa* and MRSA, were made by all participants. In making decisions participants described balancing quality of life with risk to health. Participants generally demonstrated poor understanding of their own infection status and the specific nature of the infections, with none able to accurately describe *Burkholderia cepacia* complex. Concern about increased risk of infection was seldom a deciding factor in decision making but misconceptions held about level of risk meant participants were rarely making an informed decision.

346* Health related quality of life (HRQoL) and health utility in patients with cystic fibrosis (CF) and chronic *Pseudomonas aeruginosa* (PA) infection in the UK

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Objective: To obtain HRQoL and health state utility values for adult patients with CF and chronic PA infection.
Methods: Patients taking nebulized or oral antibiotics were recruited from 5 CF centres in UK. They were classified at study entry by their exacerbation status: acute pulmonary exacerbation (APE) treated in hospital (severe), treated at home (mild) or no exacerbation (none). All patients completed the Cystic Fibrosis Quality of Life-Revised (CFQ-R) and EuroQol-5D (EQ-5D).
Results: Data was collected on 94 patients, 51% male, mean(SD): age 28.5(8.2) yrs; FEV_1 58.7(26.8)%. Among these patients, 17 had a severe APE, 13 had a mild APE, 58 had no APE and for 6 the information was missing. CFQ-R scores reported according to APE status showed that the worse the exacerbation status, the lower the mean CFQ-R scores for the 12 domains and the poorer the quality of life (exceptions on 'eating disturbance' and 'digestion'). Similar findings were shown for the EQ-5D utility and VAS mean scores confirming that patients with more severe APEs have poorer HRQoL. EQ-5D utility means (95% CI, beta distribution) were 0.58 (0.42, 0.73) for severe APE, 0.78 (0.65, 0.89) for mild APE, and 0.84 (0.80, 0.88) for those with no APE. For comparison the mean UK general population norms (age 25–44 is 0.94–0.91).
Conclusions: In CF patients with chronic PA infection the APE status influences HRQoL as measured by CFQ-R and EQ-5D. As exacerbation status worsens patients experience worse HRQoL.
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347* Communication and information about reproductive and sexual health in cystic fibrosis: a review

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Background: This review aimed to evaluate research on communication and information about reproductive and sexual health (RSH) in cystic fibrosis (CF).
Methods: All papers in the English language reporting reproductive and sexual health issues in CF, published between January 2000 and December 2010 were included. The review focused on (a) the content of information given to parents and patients; (b) the sources of information for parents and patients; (c) the timing of information; (d) health care professionals', patients' and parents' emotional reactions and attitudes toward communicating about RSH and (e) cultural and ethical considerations.
Results: Eleven papers were identified. The study populations were: male patients (5 papers), female patients (1 paper), mixed sample of male and female patients (1 paper), health care professionals (1 paper), mixed sample of parents and female patients (2 papers) and parents of male patients (1 paper). Patients with CF and their parents express embarrassment to initiate a discussion about RSH. They also express the need for more specific and up-to-date verbal and written information, at appropriate time points, provided by the CF team and infertility specialists. Healthcare providers also express embarrassment and a need for training to counsel patients in RSH.
Conclusion: Pro-active discussion of RSH issues with patients and reproductive counselling is proposed to be a standard part of the care-path. A list of recommendations is given to ensure that patients and parents receive the information they need.